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Measuring stigma in chronic pain: Preliminary investigation of instrument psychometrics, correlates, and magnitude of change in a prospective cohort attending interdisciplinary treatment

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Abstract

Chronic pain is a potentially stigmatizing condition. However, stigma has received limited empirical investigation in people with chronic pain. Therefore, we examined the psychometric properties of a self-report questionnaire of stigma in people with chronic pain attending interdisciplinary treatment. Secondarily, we undertook an exploratory examination of the magnitude of change in stigma associated with interdisciplinary treatment in a prospective observational cohort. Participants attending interdisciplinary treatment based on Acceptance and Commitment Therapy completed the Stigma Scale for Chronic Illness eight-item version (SSCI-8; previously developed and validated in neurological samples), and measures of perceived injustice, pain acceptance, and standard pain outcomes before (n=300) and after treatment (n=247). A unidimensional factor structure and good internal consistency were found for the SSCI-8. Total SSCI-8 scores were correlated with pain intensity, indices of functioning, and depression in bivariate analyses. Stigma scores were uniquely associated with functioning and depression in multiple regression analyses controlling for demographic factors, pain intensity, pain acceptance, and perceived injustice at baseline. SSCI-8 total scores did not significantly improve following treatment, although an exploratory subscale analysis showed a small improvement on internalized stigma. In contrast, scores on perceived injustice, pain acceptance, and pain outcomes improved significantly.

Taken together, these data support the reliability and validity of the SSCI-8 for use in samples with chronic pain. Further research is needed optimise interventions to target stigma at both the individual and societal levels.

Perspective: This study supports the use of the SSCI-8 to measure stigma in chronic pain. Stigma is uniquely associated with worse depression and pain-related disability. Research is needed to identify how to best target pain-related stigma from individual and societal perspectives.

Key Words: Stigma, injustice, chronic pain

Introduction

A recent proposal to update the definition of pain states that "[pain] is a distressing experience associated with actual or potential tissue damage with sensory, emotional, cognitive, and social components."[64] This definition highlights the central role of social processes in the pain experience. Consideration of the social context is crucial to understand patients' adaptation to chronic pain. Supportive social environments, such as those characterized by empathy and validation, may foster well-being among people with chronic pain.[6] In contrast, punitive or stigmatizing responses or lack of support may exacerbate pain-related disability.[3, 5, 11, 18] There are likely complex interactions between a person's behavioral responses and the social context within which he or she adapts to pain.[26]

The potentially adverse impact of a social environment characterized by stigmatizing responses has been identified as an area of importance for research and clinical practice in chronic pain.[11, 63] Stigma describes devaluing and discrediting responses toward a person or group perceived to possess a negative attribute that deviates from social norms and involves elements of social exclusion and embarassment.[11, 23] Stigma has also been described as comprising "enacted" and "internalized" stigma.[48, 49] Enacted stigma refers to negative attitudes expressed by others toward the stigmatized person or group, while internalized stigma occurs when that person or group comes to believe these negative self-referential attitudes.[44] Previous studies of the Stigma Scale for Chronic Illnesses (SSCI) in people with neurological conditions found that a single factor underlies facets of internalized and enacted stigma.[44, 48] However, another study assessing internalized

and enacted stigma in people with HIV found support for separate factors.[50] Therefore, it is unclear whether stigma as measured by the SSCI is better conceived as unidimensional or multifaceted.

Chronic pain in the absence of clear pathophysiology may set the stage for stigmatizing responses.[11, 16] Evidence from interview studies suggests that people with chronic pain feel their pain is not understood by others, including friends, family, employers, healthcare practitioners, and society at large.[33, 53] Moreover, experimental studies show that lay observers and healthcare professionals underestimate the pain of others and devalue their personal attributes when pain occurs in the absence of a medical explanation.[12, 13]

Despite the clear relevance of stigma few studies have directly investigated it in relation to chronic pain outcomes.[11] Related research on perceived invalidation suggests that reports of discounting responses from others are associated with reduced emotional, social, and physical functioning in people with rheumatoid arthritis and fibromyalgia.[32] Research on perceived injustice (i.e., perceptions that pain is not understood by others, a sense of unfairness, and blame) also highlights the detrimental impact of stigma-related constructs on pain and related disability.[56] However, measures of perceived invalidation and injustice were not designed to specifically assess stigma and do not address key aspects such as social exclusion and embarrassment.

At present, a measure of stigma has not been comprehensively validated in people with chronic pain. Moreover, data are lacking to assess the unique associations between stigma and pain outcomes independent of its association with

related constructs, such as perceived injustice and pain acceptance, which reflects openness to pain-related experiences and engagement in valued activities in the presence of pain.[42] Finally, little is known about the extent to which stigma changes in the context of interdisciplinary rehabilitation for chronic pain. Theoretically, Acceptance and Commitment Therapy (ACT) may improve aspects of stigma through helping people to develop skills to reduce the impact of stigma-related thoughts and feelings and to engage in personally meaningful activities in the face of stigma.[40]

The purpose of this study was to examine the psychometric properties of a brief self-report questionnaire of stigma in people with chronic pain attending interdisciplinary treatment. We aimed to ascertain the factor structure of the Stigma Scale for Chronic Illnesses (8-item version; SSCI-8) and to determine its reliability in the current sample. In support of its validity in a chronic pain sample, we predicted that the SSCI-8 would be positively associated in cross-sectional analyses with pain, disability, depression, and perceived injustice and negatively associated with pain acceptance. Secondarily, we undertook an exploratory examination of the magnitude of change in stigma associated with interdisciplinary treatment based on Acceptance and Commitment Therapy (ACT) for chronic pain.

Materials and Methods

Participants

Participants (n=303) were adults with chronic pain consecutively attending an interdisciplinary, residential pain management treatment programme at St. Thomas' Hospital in central London, UK between June 2016 and July 2017. The sample size

was determined pragmatically based on the number of patients attending treatment during this time period. The treatment programme lasted three or four weeks. Participants were referred to the pain management programme from primary or secondary care. All participants were assessed by both a physiotherapist and psychologist to determine their suitability for the programme. The programme was aimed at improving functioning and quality of life with pain rather than on pain reduction. The treatment programme offered was based on principles of ACT for chronic pain.[41]

Participants were eligible for the pain management programme if they were at least 18 years old, had chronic pain ($\geq$3 months duration) which significantly impacted on their mood and/or functioning, and were willing and able to participate in a group treatment setting, including speaking and understanding English. Participants were excluded if they were pursuing or awaiting further medical assessments or interventions for managing pain. They were also excluded if they had any medical or psychological factors judged to substantially limit their ability to engage safely and effectively with the treatment programme, such as active psychosis, severe affective disorder, dementia, active suicidal intent, or addiction. Participants were also excluded if they were not able to independently self-care.

Procedure

This was a prospective, observational cohort design. Participants completed standard baseline assessment measures in clinic at the start of their treatment programme. The measures assessed background information including gender, age,

ethnicity, pain location and duration, living situation, years of education, and work status. At the baseline assessment participants also completed standard pain outcome measures, the measure of stigma, and other psychological processes used to validate the stigma measure. These variables were assessed in the same way post-treatment. Signed informed consent was obtained from each participant to use his or her data for research purposes. Throughout this procedure, trained service staff were available to provide support and any explanations when required. This process facilitated data completeness. The use of a consecutive sample of participants, standardised and previously validated questionnaires, and procedures to reduce missing data were all efforts to minimise bias in the study. The research database and study were granted ethics and National Health Service Research and Development approvals.

Treatment

The pain management treatment is an interdisciplinary version of ACT, an approach that aims to improve patient functioning through increased psychological flexibility.[41] The team included psychology, physiotherapy, occupational therapy, and nursing components. The focus on psychological flexibility in ACT includes helping participants develop skills in openness towards experiencing pain and unwanted feelings, present-focused awareness, values-based and committed action. The focus on openness is in contrast to a focus on reducing pain, or unwanted feelings and thoughts. Psychological flexibility is enhanced through experiential exercises, exposure-based methods, metaphors, mindfulness practices, cognitive defusion

techniques, and other values and goal-focused methods.[41] Pain education is integrated throughout the programme, but is not the overriding focus. Treatment was provided in a group format. Partners and family members were invited to attend a session to explore the impact of pain on relationships and how the "open, aware, and engaged" skills can be used to foster better relationships.

Treatment content on stigma and perceived injustice are not formally manualized as part of the treatment; however, such topics inevitably arise. Consistent with the treatment model, the treatment team responds to discussions surrounding stigma in a way that fosters psychological flexibility: namely, helping people become open and aware of the experiences and impact of stigma, exploring the helpfulness of struggling to avoid or control stigma-related thoughts and feelings, and practicing engagement in values-based activities alongside stigma. It is plausible that increased engagement in values-based activities may contribute to reduced self-stigma. For example, feelings of pride and accomplishment from pursuing personally-meaningful activities may register more prominently than feelings of embarrassment. Participation in the group-based format may also foster a sense of validation and inclusion that could reduce stigma.

Assessment Measures

Stigma Scale for Chronic Illnesses - Eight Item Version (SSCI-8): The SSCI-8 is an eight-item measure of stigma that assesses components of both enacted (e.g., "Because of my illness, people were unkind to me") and internalized stigma (e.g., "I felt embarrassed because of my physical limitations").[44, 48] To facilitate comparisons with

the original validation study, we retained the exact wording of the SSCI-8 items which refer to one's illness in general rather than the specific diagnosis of the sample.[44] Each item is rated with the following response format: 1 = never, 2 = rarely, 3 = sometimes, 4 = often, and 5 = always. The scale has previously shown good internal consistency (total score Cronbach's α=0.89), and validity in relation to psychological distress in people with neurological conditions.[44] The SSCI-8 total score has previously been used to assess the association between stigma and outcomes such as psychological distress and daily functioning.[44] Higher scores on the measure reflect greater stigma.

Pain Intensity: Participants rated the average intensity of pain over the past week on a scale with the endpoints 0 (no pain) to 10 (worst possible pain).

Patient Health Questionnaire (PHQ-9): The PHQ-9 is a measure of depression symptom severity, reflecting features of depression as defined in standard diagnostic criteria.[35] Nine items are rated on a 4-point scale ranging from 0 (not at all) to 3 (nearly every day). The PHQ-9 is considered a reliable and valid measure for assessing the severity of depression symptoms.[35]

Brief Pain Inventory (BPI) pain interference subscale: The BPI pain interference subscale is a seven-item measure of the impact of pain on daily functioning.[8] Interference from pain is rated in the following seven areas: general activity, mood, walking ability, normal work, relationships with other people, sleep, and enjoyment

of life. All seven items are rated from 0 (does not interfere) to 10 (completely interferes).[8] This measure is regarded as a reliable and valid index of chronic pain-related interference with daily functioning.[8, 31] Higher scores on the measure reflect greater pain-related interference.

Work and Social Adjustment Scale (WSAS): The WSAS is a five-item measure that assesses functional impairment associated with one's health condition in terms of work, home management, social leisure, private leisure, and personal or family relationships.[45] The WSAS items provide more in-depth assessment of functioning in occupational and leisure activities and social relationships than the BPI, while the BPI assesses functioning in domains not captured by the WSAS (e.g., sleep, walking). Therefore, both measures were used to more fully capture participants' functioning. WSAS items are rated from 0 (no impairment) to 8 (very severe impairment). The WSAS is regarded as a reliable and valid measure for assessing functioning in people with long-term health conditions.[7, 45] Cronbach's alpha ranges from 0.70 to 0.94 for this measure.[45] Higher scores on the measure reflect more severe impairment in work and social functioning.

Injustice Experiences Questionnaire (IEQ): The IEQ is a 12-item measure that assesses pain-related perceptions of injustice.[57] Perceived injustice is defined as an appraisal comprising elements of the severity of pain-related loss ("My life will never be the same"), blame ("I am suffering because of someone else's negligence"), and a sense of unfairness ("It all seems so unfair").[57] Previous research supports the

reliability and validity of the IEQ in people with chronic musculoskeletal pain.[54, 57] Higher scores on the measure reflect greater perceived injustice. Some item content of the IEQ conceptually relates to aspects of stigma (e.g., "I worry that my condition is not being taken seriously).[57] Therefore, this measure was used to assess convergent construct validity of the SSCI-8, and it was expected that the IEQ would be positively correlated with the SSCI-8.

Chronic Pain Acceptance Questionnaire-Eight Item Version (CPAQ-8): The CPAQ-8 was used to measure pain acceptance, which reflects refraining from unsuccessful attempts to avoid or control pain, and focusing on engaging in valued activities in the presence of pain.[42] Pain acceptance maps onto the "open" and "active/engaged" facets of psychological flexibility.[28] Each of the eight items is rated on a scale from 0 'never true' to 6 'always true', with higher scores reflecting greater pain acceptance. The CPAQ-8 demonstrates good internal consistency (alpha from 0.77-0.89)[19], and shows good convergent validity with the original CPAQ.[19, 52] The CPAQ-8 was used as an additional measure of construct validity. It was assumed that the SSCI-8 and CPAQ-8 would be negatively correlated. This is on the premise that the aversive quality of stigma may, understandably, enhance a person's inclination to resist or avoid pain-related experiences, rather than accept or respond openly to them.

Statistical analysis

Descriptive statistics were computed for baseline demographic variables. For pre- and post-treatment SSCI-8 data, we conducted exploratory item factor analyses

(IFA)[65] based on the polychoric correlation matrix using FACTOR version 10.3.01[39], including a principle component analysis estimator. The assumption of multivariate normality is easily violated with categorical item level data. Therefore, models for continuous data are not appropriate here. IFA is a suitable alternative to the common linear factor model for categorical item responses as it uses polychoric rather than Pearson correlations.[43] We conducted exploratory (EFA) rather than confirmatory factor analyses (CFA) as the factor structure of the SSCI-8 has been previously tested in people with neurological conditions, such as epilepsy, multiple sclerosis, and Parkinson's.[44] These diseases vary significantly from chronic pain in terms of the objective versus subjective nature of diagnosis and nature of symptoms. Additionally, there have been inconsistencies in the factor structure across studies with some reporting a single factor[44] and others report a two factor structure of internalized and enacted stigma.[50]

IFA is a re-parametrization of an item response model (Item Response Theory; IRT).[51] As such, item response difficulty and discrimination parameters were computed. In IRT, the relation between latent trait levels and the probability of a person endorsing an item in a trait-consistent manner is expressed by the item information curve.[17] The item difficulty parameter (D) is used to reflect the points on the scale of the latent trait where the probability of endorsing one category is equal to that of endorsing the next category. The item discrimination parameter is related to the factor loading and reflects how sensitive the item is to changing levels of the underlying continuous trait.

Parallel analysis (PA), which is a superior alternative to the eigen value greater than 1 rule and Scree plot, was conducted to determine the number of factors to retain.[29, 36] PA uses a random sampling of correlation matrices and compares eigenvalues extracted from the observed correlation matrix with those from the correlation matrices of the simulated normal random samples that parallel the observed data in terms of sample size and number of variables. A factor was considered significant if the associated eigenvalue was bigger than the mean of those obtained from the random uncorrelated data.[29, 36] Factor loadings were interpreted as the correlation between the item and the latent factor. Reliability was estimated using Bock and Mislevy's statistic[1], which describes the proportion of variance in a group of items' factor score accounted for by the underlying latent variable.

Pearson's correlations were performed to examine stigma scores in relation to continuous demographic variables. Independent samples t-tests were used to compare stigma between participants with respect to their gender, ethnicity (white or minority), work status (working or not working), and their sickness/disability income status (receiving or not). A one-way ANOVA was performed to compare stigma amongst participants with different primary pain sites (back, generalized, or other). Pearson correlations were computed between baseline stigma and measures of perceived injustice and pain acceptance to assess construct validity. Correlations with pain interference (BPI), work and social functioning (WSAS), and depression (PHQ-9) were computed to assess criterion validity. Correlations were interpreted as small (r=0.10), medium (r=0.30), and large (r=0.50*)*.[9]

Hierarchical regression analyses with pain interference, work and social functioning, and depression as dependent variables were performed to explore the unique associations between baseline stigma and standard pain outcomes.[15] Demographic factors and pain intensity were entered in the first and second steps of the models, respectively, to provide a more conservative estimate of the additional variance accounted for by the psychosocial variables. Pain acceptance was entered in the third step before perceived injustice and stigma, as pain acceptance is a more established correlate of pain outcomes. Perceived injustice and stigma were entered together in the final block given their conceptual similarities.

Finally, a series of paired *t*-tests were conducted to investigate the magnitude of change in all variables from baseline to post-treatment. Within-subject effect sizes (*d*) were calculated using Dunlap et al.'s formula based on the repeated-measures t-test.[14, 46] Cohen's thresholds for effect sizes were adopted: *d*=0.20 is considered as small effect size, *d*=0.50 medium, and *d*=0.80 large.[9]

Results

3.1 Data completeness and demographic characteristics

303 participants gave consent for the use of their data and were included in preliminary analyses. All variables included in the analyses were examined for skewness, kurtosis, and missingness. All variables were considered approximately normally distributed and unimodal. Twenty-four participants were missing complete data for SSCI-8, thirty for the IEQ, seventeen for the CPAQ-8, ten for the BPI, nine for the WSAS, and seventeen for the PHQ-9. Two participants scored out of range on

two items of the IEQ. Therefore, they were considered missing data on these two items. Three participants did not provide any data on any of the variables examined. Therefore, these three participants were not included in the main analyses. Amongst the remaining participants (N=300), 46 participants did not complete the treatment, and a further seven to thirteen did not provide post-treatment data for the variables included in the analyses. Participants who did and did not provide post-treatment data did not differ on SSCI-8 scores at baseline $t(291)=.71$, p=.48. All missing data were deleted pairwise in the correlations, regression analyses, and *t*-tests. As FACTOR version 10.3.01 does not allow missing data, only cases with complete data for the SSCI-8 were included in the exploratory item factor analysis (n=279 and n=236 for baseline data and post-treatment data respectively).

The study sample was comprised predominantly of women (68.3%) and participants of white British/European descent (74.3%). Participants had a mean age of 45.22 years (*SD*=12.55) and longstanding pain (*M*=13.37 years, *SD*=10.29). Back pain (42.7%) and generalized pain (26.7%) were the most frequent primary pain locations. Further demographic details are shown in Table 1.

3.2 Item factor analysis

To investigate the dimensionality of the SSCI-8, the items were submitted to item factor analysis with oblique rotation and parallel analysis. Given that items within the SSCI-8 were conceptualized along two dimensions (i.e., enacted and internalized stigma), a two-factor solution was initially specified in the modelling.[44] When a two-factor solution was applied, four items primarily loaded onto one

factor, explaining 35.3% of the variance, and three items primarily loaded onto the other factor, explaining an additional 25.5% of the variance. One item showed cross-loadings onto both factors, which limits the interpretability of the two-factor solution. The two factors were moderately correlated, *r*=0.48, and showed good reliability, 0.89, 0.85 respectively. Supplementary Table 1 shows the factor-loading pattern when a two-factor solution applied. In addition to the issue of cross-loading with the two-factor solution, results from parallel analysis suggested a one-dimension solution is superior. As results from the parallel analysis indicated a one-factor solution, the IRT parameters for the two-factor solution were not examined here. IFA was conducted again with a one-dimension solution specified in the modelling. When a one-dimension solution was applied, all items sufficiently loaded onto the factor, achieving 56.7% variance explained, and good reliability, 0.89 which further supports the suitability of the one-factor solution.

The item discrimination parameters showed a similar pattern as factor loadings. For instance, item 5 showed the highest loading onto the factor, as well as the highest item discrimination, indicating that this item is the most sensitive in differentiating the level of the underlying dimension. The item difficulty parameters were generally spread along the “trait” continuum. The item difficulty parameters for between each two response categories varied, indicating that some items are more difficult in the lower end of the continuum, and some items are more difficult in the middle or higher end of the continuum. Table 2 shows the factor-loading pattern when a one-factor solution applied, and the IRT parameters with baseline and post-treatment data.

IFA was conducted again with post-treatment SSCI-8 data to further validate its structure. Overall, these analyses produced comparable results with improved psychometric properties. Again, PA suggested a one-factor solution. When a one-factor solution was applied, all items loaded sufficiently onto the factor, with good reliability (0.89), explaining 55.3% of the variance. Overall, these results suggest the uni-dimensionality of the SSCI-8, and an adequate quality of the items included in the scale.

3.3 Validity

The SSCI-8 was significantly correlated with age, r=-0.21, p<0.001, but not years of education, r=0.03, p=0.662. It was not significantly correlated with pain duration, r=-0.09, p=0.135. Stigma scores did not differ significantly between women (M=21.88, SD=6.89) and men (M=21.24, SD=5.95), t(290)=-0.77, p=0.44, nor did stigma differ between white participants (M=21.51, SD=6.21) and those from an ethnic minority background (M=22.21, SD=6.93), t(287)=-0.76, p=0.45. Participants who were working showed significantly lower stigma scores (M=20.49, SD=5.97) than those who were not (M=22.31, SD=6.85), t(283)=-2.19, p=0.03. Participants who were receiving sickness or disability-related income showed significantly higher stigma scores (M=22.91, SD=6.75) than those who were not (M=18.99, SD=5.41), t(216)=5.25, p<0.001. There was a significant general effect of primary pain site on stigma scores, F(2, 272)=6.24, p=0.002. When post-hoc comparisons were examined, a significant difference was observed between participants with back pain (M=20.21, SD=6.47) and those with generalized pain (M=23.42, SD=6.54), p=0.002.

Table 3 shows the correlations between SSCI-8 the other self-report measures. The total SSCI-8 score significantly correlated with perceived injustice (large correlation) and pain acceptance (medium correlation) in the expected directions, demonstrating convergent construct validity. The SSCI-8 total score also had a small but significant correlation with pain intensity and showed significant medium-sized correlations with pain-related interference, work and social functioning, and depression. Except for a non-significant correlation between pain intensity and pain acceptance, the other self-report measures were all significantly inter-correlated (medium to large magnitude).

Hierarchical regression analyses are shown in Table 4. Only demographic variables that were significantly associated with stigma in bivariate analyses were entered in the first step. We did not conduct a regression analysis with pain intensity as the dependent variable given the weak bivariate correlation between pain intensity and stigma; however, pain intensity was included as a covariate in the regression analyses. After controlling for demographic variables, pain intensity explained significant additional variance, 8% to 30%, in all models. In the third step, pain acceptance was significant and explained an additional 5 to 10% of the variance in the three models. After controlling for background variables, pain intensity, and pain acceptance, stigma and perceived injustice together contributed an additional 4% of the variance to work and social impairment, a further 6% of the variance to pain interference, and an additional 12% of the variance to depression. In the final regression equation containing all independent variables simultaneously, both

stigma and perceived injustice remained significant unique correlates of all three outcomes.

3.4. Magnitude of change in stigma from pre- to post-treatment

Means and standard deviations for the SSCI-8 and other questionnaires at baseline and post-treatment are shown in Table 5. Paired *t*-tests showed no change in stigma total scores from pre- to post-treatment. In contrast, perceived injustice and pain acceptance improved with small and moderate effects, respectively. Improvements for standard pain outcomes were moderate to large.

Despite finding support for a one factor model in our study, it is pragmatic to use the internalized and enacted subscales to evaluate the potential suitability of stigma targeting interventions at the individual versus societal level.[44] Therefore, we conducted an exploratory investigation of the relative magnitude of change in the subscales from baseline to post-treatment. When using the two-factor structure, the SSCI-8 generally showed a loading pattern consistent with the proposed classification of enacted and internalised stigma in the previous validation study.[44] However, item 1 ("Because of my illness, some people avoided me") showed cross loadings in our sample, and item 2 ("Because of my illness, I felt left out of things."), which was cross-loaded in a previous study [44, 48], loaded onto internalized stigma in the current sample. Therefore, the subtotal scores of the SSCI-8 were calculated, with item 1 categorised as enacted stigma as in the previous study, and item 2 categorised as internalized stigma. Enacted stigma did not change significantly from pre- (M=11.11, SD= 4.35) to post-treatment (M=11.43, SD=4.30), t(235)=-1.2, p=0.23,

d=0.07. However, participants showed a significant decrease in internalized stigma from pre- (*M*=10.25, *SD*=2.73) to post- (*M*=9.65, *SD*=3.28) treatment, with a small effect size (*d*=0.20), *t*(235)=2.85, *p*=0.005.

Discussion

The purpose of this study was to conduct a preliminary investigation of the psychometric properties of a measure of stigma, the SSCI-8, in a relatively large sample of adults with chronic pain. We found that the SSCI-8 items captured differing levels of the underlying stigma dimension, and we found evidence for a unidimensional factor structure and good internal consistency, consistent with the validation study in neurological samples.[44] Thus, while the SSCI-8 items have content reflecting both internalized and enacted aspects of stigma, these facets are closely related in people with chronic pain and appear to reflect a single construct. The current data provide preliminary support for using the SSCI-8 total score in samples with chronic pain. SSCI-8 total scores were positively correlated with pain intensity, indices of functioning, and depression in bivariate analyses, and were uniquely associated with functioning and depression in multiple regression analyses. Taken together, these data support the reliability and validity of the SSCI-8 for use in samples with chronic pain.

The mean pre-treatment SSCI-8 total score in our sample (*M*=21.35*, SD*= 6.30) was approximately five to nine points higher than the means reported in the initial validation study in people with amyotrophic lateral sclerosis (*M*=15.51, *SD*= 5.47), stroke (*M*=14.75, *SD*=7.16), epilepsy (*M*=14.56, *SD*=7.03), multiple sclerosis (*M*=12.23, *SD*=4.34), and Parkinson's (*M*=12.07, *SD*=4.28).[44] The current sample

(*M*=31.84, *SD*=9.96) also scored above the cut-off (≥19) for perceived injustice.[54] Thus, our sample reported high levels of stigma and perceived injustice.

Results in this study from a population of people with heterogeneous chronic pain conditions are similar to studies of people with rheumatoid arthritis and fibromyalgia showing adverse impacts on functioning from reports of invalidating responses from others.[32, 33] Our findings are also similar to one study that measured internalized stigma and found this was associated with greater disability and depression in a relatively small sample of people with chronic pain.[61] The current findings are consistent with results from experimental studies generally showing the adverse impacts of invalidating responses to pain[18] and with recent theorizing around the impacts of stigma in chronic pain.[11] The current results extend previous work by examining the psychometric properties of a measure of stigma, examining stigma in relation to conceptually-relevant psychosocial constructs (e.g., perceived injustice), and investigating the magnitude of change in stigma associated with an interdisciplinary ACT-based rehabilitation program.

Analyses showed SSCI-8 total scores were significantly positively correlated with perceived injustice and negatively correlated with pain acceptance, both in the expected direction. These findings provide support for the construct validity of the SSCI-8. Multivariate regression analyses showed that the SSCI-8 remained significantly uniquely associated with pain interference, impairment in work and social functioning, and depression, after controlling for demographic factors, pain intensity, pain acceptance, and perceived injustice. These results suggest that stigma as measured by the SSCI-8 contributes unique information to the understanding of

important pain outcomes above and beyond more established and related processes. For this measure of stigma to remain significantly associated with key outcomes independent of robust covariates represents a high standard of performance and supports its potential usefulness for asking new questions about psychosocial processes in relation to chronic pain.

Analyses of the magnitude of change associated with an ACT-based interdisciplinary treatment showed that while perceived injustice, pain acceptance, and standard outcomes improved, stigma total scores did not. Exploratory subscale analyses revealed that, although there was no improvement on enacted stigma, the internalized stigma subscale showed a small improvement. Previous studies of ACT in people with chronic pain show improvements in a wide range of outcome measures, including pain-related disability and depression[27, 58], sleep[10], directly assessed physical performances,[25] and medication use.[24] In the current study we have shown, perhaps for the first time, that an ACT-based treatment is also associated with a small decrease in perceived injustice. The magnitude of change in perceived injustice reported here is similar to that reported in a traditional CBT protocol[55] and, in both studies, is relatively smaller than the magnitude of change for other psychological processes. Due to the wide-ranging improvements associated with ACT for pain, it was somewhat unexpected to find no effect of this treatment on stigma total scores.

There are arguments from which to presume ACT might have a positive impact on stigma. Theoretically, the core therapeutic processes of ACT are intended to enable people with pain to contact negative judgements and interactions with

openness and wider awareness, and to not take them to heart, so to speak.[34] Given the demonstrated benefits of ACT for emotional, physical, and social functioning, one might predict that this could reduce instances of stigmatizing behaviour from others. This is based on the reasoning that better, healthier, functioning might make others unable to detect reflections of pain, distress, and disability on which they can impose negative judgements and interactions. However, it is equally plausible that patients face further stigma when they engage in more functional patterns of behavior in the presence of pain, as this might represent evidence of the 'illegitimacy' of pain to outside observers.[62] Another hypothesis is that ACT might not directly affect cognitive or emotional content related to stigma as measured by the SSCI-8, but rather it improves engagement in more adaptive behaviours in the presence of these experiences.[34] Finally, it may be that a general approach within ACT for chronic pain is not specifically targeted enough to impact stigma, and perhaps more specific customizing of ACT for stigma is needed.

As mentioned, the current data support the use of a single total score on the SSCI-8 in samples with chronic pain. However, there may be practical reasons for which researchers and clinicians may choose to use the enacted and internalised stigma subscales. For example, understanding the relative impact of internalized and enacted stigma can inform the need to intervene at the level of the individual, community, healthcare system, professional training, policy, or all of the above.[44] Despite also finding a unidimensional structure, the use of subscales for these pragmatic reasons is consistent with the recommendations from the initial SSCI-8 validation study.[44]

An approach to intervention that focuses solely on the person's response to stigma, rather than on broader sociocultural issues that feed into stigma is likely to be suboptimal.[63] It is noteworthy that participants receiving disability benefits in our study showed significantly higher levels of stigma than those not receiving benefits (medium effect size). Particularly in the UK context, there is deep-rooted suspicion around people who receive disability benefits and this is ingrained in highly stigmatizing social policies.[21, 22] Therefore, strategies that reduce pervasive rhetoric and policies that demean and threaten the social inclusion[30] of people with chronic pain are needed to address stigma. Intervention strategies that foster empathy, validation, and compassion for people with pain by healthcare professionals, partners, and the general public may also prove beneficial.[4, 37] The active involvement of a range of stakeholders in co-producing policies and interventions may optimise our ability to tackle stigma. For this we may look to other areas of health, such as the HIV response, that have used such strategies to tackle stigma with great benefit.[2, 38, 47]

Future research might take a deeper look at several aspects of stigma. One aspect is to uncover the processes by which stigma exerts its impact on daily emotional, physical, and social functioning for people with chronic pain. If these could be identified, it could provide a basis for intervening to reduce the impact of stigma. It would also be informative to investigate the function of stigma in different contexts, such as pain which occurs as the primary diagnosis and pain in the context of other highly stigmatized conditions, such as HIV. For example, people living with HIV and pain may be particularly likely to engage in efforts to conceal pain because

of HIV stigma,[59, 60] while those with a primary pain diagnosis may feel they are constantly trying to credibly "prove" the existence of pain.[62] Finally, it almost goes without saying, there is a need to better understand the roots of stigmatizing behaviour toward people with chronic pain at the point of delivery. Greater understanding of the processes which feed the insensitivity and invalidating behavior of the stigmatizers may improve our ability to intervene at the social level.

The current study has several limitations. First and foremost, all the measures were collected by self-report. This can reduce measurement accuracy and enhance apparent relations. Research participants are imperfect in reporting on their own behavior and the treatment context or the health conditions present can impose influence. The challenge here is that, at present, it is difficult to more directly assess a person's experience of stigma, or similar processes, except by asking them. Second, causal relations cannot be inferred here due to the observational research design. We conducted exploratory factor analyses as a preliminary investigation of the structure of the SSCI-8 in a chronic pain sample. We did not have a sufficiently large sample to conduct a random split of the sample to allow for exploratory factor analyses to be followed by confirmatory analyses. Therefore, confirmatory factor analyses of the SSCI-8 in other chronic pain samples is needed. We did not compute test re-test reliability for the SSCI-8 at pre- and post-treatment as it was assumed that participants' health status and psychosocial functioning would change during the intensive rehabilitation programme. To adequately judge the test re-test reliability of the SSCI-8 in people with chronic pain, future research is needed to administer the measure at two time points in the absence of treatment.[20] Finally,

the population here is both diverse in some respects, such as the types and duration of pain conditions, and very specific, including predominantly women and white British/European adults seeking speciality services for pain in central London, UK. Therefore, determining the generalizability of these results to other groups of people is needed.

In summary, stigma appears relatively common in people seeking treatment for chronic pain. A measure of stigma studied here (the SSCI-8) appears psychometrically adequate for further use in samples of people with chronic pain. Use of the SSCI-8 total score is supported by the single factor structure identified here; however, internal and external stigma subscales may be pragmatically useful to identify the need for specific interventions. Scores from this measure appear both related to measures of similar concepts, such as perceived injustice and pain acceptance, and unique from them in their association with pain outcomes. These results warrant the conclusion that a distinct process is being assessed. Scores on this measure of stigma, on average, did not significantly shift in an ACT-based treatment for chronic pain. This may mean the ACT treatment is inert with respect to this process or is not customized well enough. Future research is needed to understand the processes by which stigma impacts on important pain outcomes. Research into interventions that target aspects of the social environment that feed into stigma is needed to optimally impact the lives of people living with chronic pain.

Table 1. Demographic characteristics of the sample.

		Mean (SD) or *n* (%)
Gender	Women	205 (68.3%)
	Men	94 (31.3%)
Age (years)		45.22 (12.55)
Ethnicity	White	223 (74.3%)
	Black	37 (12.3%)
	Mixed/Other	18 (6.0%)
	Asian	17 (5.7%)
Living status	With partner and children	95 (31.7%)
	Alone	74 (24.7%)
	With partner	52 (17.3%)
	With children	39(13%)
	Other relatives	27 (9.0%)
	With friends/flatmates	10 (3.3%)
Years of education		13.98 (3.70)
Work status	Unemployed because of pain	161 (53.7%)
	Employed full time	30 (10%)
	Employed part time due to pain	30 (10%)
	Homemaker	17 (5.7%)
	Unemployed for other reason	8 (2.7%)
	Unpaid volunteer	5 (1.7%)
	In other training	4 (1.3%)
	Employed part time--other	3 (1.0%)
	Carer	2 (0.7%)
	Retired	2 (0.7)
	Student	1 (0.3%)
Disability income		199 (66.3%)
Current legal action related to pain		17 (5.7%)
Pain Duration (years)		13.37 (10.29)
Primary pain location	Lower back/spine	128 (42.7%)
	Generalized	80 (26.7%)
	Lower limbs	28 (9.3%)
	Upper shoulder/limbs	16 (5.3%)
	Neck region	13 (4.3%)
	Head, face or mouth	4 (1.3%)
	Abdominal region	4 (1.3%)
	Pelvic region	3 (1.0%)
	Anal/genital	3 (1.0%)
	Chest region	2 (0.7%)

Table 2. The factor-loading pattern and IRT parameters for the SSCI-8 one-factor solution with baseline and post-treatment data.

	Baseline							Post-treatment						
Item	Factor loading	Item discrimination	D1	D2	D3	D4	D5	Factor loading	Item discrimination	D1	D2	D3	D4	D5
1	0.81	1.38	-3.02	-0.94	-0.35	0.76	1.99	0.81	1.39	-2.94	-0.91	-0.37	0.75	2.06
2	0.62	0.79	-5.00	-2.27	-1.69	-0.18	1.59	0.58	0.72	-5.00	-2.45	-1.85	-0.21	1.79
3	0.78	1.24	-5.00	-0.16	0.76	1.72	2.44	0.76	1.19	-5.00	-0.22	0.73	1.76	2.65
4	0.73	1.06	-5.00	-1.51	-0.88	0.22	1.17	0.70	0.98	-5.00	-1.65	-0.96	0.19	1.29
5	0.83	1.49	-5.00	-0.73	0.09	1.11	1.90	0.83	1.48	-5.00	-0.81	0.08	1.13	2.02
6	0.70	0.97	-5.00	-1.96	-1.36	-0.31	0.87	0.68	0.92	-5.00	-2.16	-1.51	-0.36	0.93
7	0.76	1.15	-5.00	-0.17	0.72	1.67	2.38	0.77	1.19	-5.00	-0.18	0.77	1.60	2.31
8	0.78	1.25	-5.00	-0.42	0.16	1.11	1.81	0.79	1.27	-5.00	-0.44	0.16	1.05	1.82

Note. IRT, Item Response Theory; SSCI-8, Stigma Scale for Chronic Illnesses-Eight Item version

D= item difficulty (D1 represents the point, on the continuum of the latent trait, at which the probability of endorsing "1" is equal to the probability of endorsing "2", D2 represents the point at which the probability of endorsing "2" is equal to the probability of endorsing "3", and so forth). For instance, for item 1 with baseline data, the level of the latent trait needs to increase by 2.08 units (D2-D1) for it to be more likely that participants endorse "2" rather than "1", while for item 2 the level of the latent trait needs to increase by 2.73 (D2-D1) unit for it to be more likely that participants endorse"2" rather than "1". This indicates that item 2 is more difficult than item 1 at the lower end of the latent trait continuum.

Table 3. Baseline correlations between SSCI-8 total scores and other self-report measures.

	CPAQ-8	IEQ	Pain	BPI	WSAS	PHQ-9
SSCI-8	-0.35***	0.52***	0.13*	0.38***	0.34***	0.41***
(N)	*291*	*293*	*292*	*292*	*293*	*293*
CPAQ-8		-0.36***	-0.09	-0.32***	-0.38***	-0.27***
(N)		*293*	*294*	*294*	*295*	*295*
IEQ			0.20**	0.38***	0.35***	0.45***
(N)			*294*	*294*	*295*	*295*
Pain				0.58***	0.33***	0.37***
(N)				*298*	*299*	*299*
BPI					0.54***	0.51***
(N)					*299*	*299*
WSAS						0.33***
(N)						*300*

Note. BPI, Brief Pain Inventory; CPAQ-8, Chronic Pain Acceptance Questionnaire, Eight Item version; IEQ, Injustice Experiences Questionnaire; PHQ-9, Patient Health Questionnaire Depression Module; SSCI-8, Stigma Scale for Chronic Illnesses-Eight Item version; WSAS, Work and Social Adjustment Scale.
*p<0.05, **p<0.01, ***p<0.001.

Table 4. Hierarchical regression analyses examining the association between stigma

and pain outcomes at baseline.

Model/Step	Independent Variable	*F* change	*df*	*p*	Adjusted R^2	β	*p*
Dependent: Pain Interference (BPI)							
1	Age	2.68	(4,249)	0.032	0.03	0.00	0.977
	Pain location (back/generalized/other)					-0.06	0.237
						0.03	0.575
	Disability income (yes/no)					0.00	0.999
	Work status (no/yes)						
2	Pain intensity	115.80	(1,248)	<0.001	0.33	0.51	<0.001
3	Pain acceptance (CPAQ-8)	26.01	(1, 257)	<0.001	0.39	-0.17	0.002
4	Stigma (SSCI-8)	13.68	(2, 245)	<0.001	0.45	0.21	<0.001
	Perceived injustice (IEQ)					0.11	0.046
Dependent: Work and Social Impairment (WSAS)							
1	Age	4.34	(4,249)	0.002	0.05	0.07	0.219
	Pain location (back/generalized/other)					0.07	0.221
						-0.05	0.415
	Disability income (yes/no)					0.00	0.973
	Work status (no/yes)						
2	Pain intensity	24.70	(1, 248)	<0.001	0.13	0.25	<0.001
3	Pain acceptance (CPAQ-8)	31.90	(1, 247)	<0.001	0.23	-0.25	<0.001
4	Stigma (SSCI-8)	7.40	(2, 245)	<0.001	0.27	0.14	0.041
	Perceived injustice (IEQ)					0.14	0.035
Dependent: Depression (PHQ-9)							
1	Age	2.37	(4, 249)	0.053	0.02	0.05	0.362
	Pain location (back/generalized/other)					0.03	0.629
						-0.02	0.726
						0.07	0.200

	Disability income (yes/no) Work status (no/yes)						
2	Pain intensity	36.10	(1, 248)	<0.001	0.14	0.28	<0.001
3	Pain acceptance (CPAQ-8)	14.98	(1, 247)	<0.001	0.19	-0.09	0.149
4	Stigma (SSCI-8)	22.68	(2, 245)	<0.001	0.31	0.22	0.001
	Perceived injustice (IEQ)					0.26	<0.001

Note. BPI, Brief Pain Inventory; CPAQ-8, Chronic Pain Acceptance Questionnaire, Eight Item version; IEQ, Injustice Experiences Questionnaire; PHQ-9, Patient Health Questionnaire Depression Module; SSCI-8, Stigma Scale for Chronic Illnesses-Eight Item version; WSAS, Work and Social Adjustment Scale. β coefficients are from the final regression equation.

Table 5. Magnitude of change in self-report variables from pre- to post-treatment.

	Pre-treatment		Post-treatment					
	M	*SD*	*M*	*SD*	*t*	*df*	*p*	*d*
Stigma (SSCI-8)	21.35	6.30	21.08	6.79	0.67	235	0.50	0.04
Perceived Injustice (IEQ)	31.84	9.96	27.91	10.96	7.15	237	<0.001	0.37
Pain acceptance (CPAQ-8)	17.02	7.61	22.46	7.49	-10.29	239	<0.001	0.72
Pain intensity	7.63	1.60	6.84	1.70	7.65	243	<0.001	0.48
Pain-related interference (BPI)	7.70	1.68	5.78	2.19	13.83	245	<0.001	0.98
Work and social adjustment (WSAS)	32.31	7.56	27.80	9.50	7.23	245	<0.001	0.52
Depression (PHQ-9)	17.83	6.19	12.54	6.13	13.93	243	<0.001	0.86

BPI, Brief Pain Inventory; CPAQ-8, Chronic Pain Acceptance Questionnaire, Eight Item version; IEQ, Injustice Experiences Questionnaire; PHQ-9, Patient Health Questionnaire Depression Module; SSCI-8, Stigma Scale for Chronic Illnesses-Eight Item version; WSAS, Work and Social Adjustment Scale.

Supplementary Table 1. The SSCI-8 factor-loading pattern for the two-factor solution at baseline.

	Item	Factor 1	Factor 2
1	Because of my illness, some people avoided me.	0.42	0.48
2	Because of my illness, I felt left out of things.	-0.07	0.81
3	Because of my illness, people avoided looking at me.	0.70	0.10
4	I felt embarrassed about my illness.	0.18	0.65
5	Because of my illness, some people seemed uncomfortable with me.	0.74	0.16
6	I felt embarrassed because of my physical limitations.	-0.02	0.84
7	Because of my illness, people were unkind to me.	0.91	-0.15
8	Some people acted as though it was my fault I have this illness.	0.78	0.04

Note: Items from the SSCI-8, Stigma Scale for Chronic Illnesses-Eight Item version[45]

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